IMPACT OF CRITICAL ILLNESS ON THE PSYCHOLOGICAL DISTRESS OF CHILDREN WHO SURVIVED MECHANICAL VENTILATION IN THE PAEDIATRIC INTENSIVE CARE UNIT OF CHRISTIAN MEDICAL COLLEGE AND HOSPITAL, VELLORE

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ABSTRACT

A study was conducted in PICU, CMC Vellore to assess the impact of critical illness on the psychological distress in children who survived mechanical ventilation. The study was conceptualised using the Roy's Adaptation Model. self-reporting questionnaire developed by Jannet E Rennick, Childrens critical illness impact scale   used in assessing the level of psychological distress of children. Pilot study was conducted to check the feasibility of the study, sample selection, and applicability of the tool in Indian scenario. The data for the main study was collected over a period of 6 weeks in Selected Paediatric wards and child heath OPD in CMC, Vellore. Total enumerative sampling method was used to select samples who fit the inclusion criteria. Data analysis was done for descriptive and inferential statistics using the statistical application, SPSS version 21.0 .

The major findings were ,majority of the children were in the age group of 6-8 years and 11-12 years(35.9%), 60.9% were boys, and most were practicing Hindu religion (60.9%), majority (71.9%) were studying in middle school. Respiratory illness is the primary reason (40.6%) for mechanical ventilation, followed by Infection (26.6%). 92.2% of the children were emergency admissions, with 82.8% of children with no pre-existing co morbidities.78.8% were on invasive mechanical ventilation and 60.9%were intubated for more than 48 hours.

- Of 64 children who participated, the minimum score that they had given to the level of psychological distress, was 40 (62.5%) children were moderately distressed and a maximum score of 24 (37.5%) were severely distressed. Of children who participated, the minimum score that they had given to the level of psychological distress, was 64(70%) and a maximum score of 88 (96 %), with a mean score of 73.4 ± 5.0

INTRODUCTION:
"Children are our greatest treasure, they are our future"

- Nelson Mandela.

"It is easier to build strong children than to repair broken men".

-Frederick Douglass

These are some quotes that talk about the need for building an environment wherein a child can grow a positive and healthy attitude, both physically and psychologically. Health, by definition means "A state of physical, mental and social well-being, not merely the absence of illness or infirmity" (WHO 1948).

BACK GROUND:
Illness, of any kind is a distressing time for the child experiencing it, critical illness more so. Critically ill children suffer from acute physiological instability due to injury or insult to the vital organs, that requires urgent treatment to avoid death or disability. Recent advancements in medical and intensive care technologies, organisational changes have modified the outcome of critical care illness, leading to decrease in mortality rates (Anna RS, 2013).The overall incidence globally of critically ill patients has been identified as 34.4 per 100,000 admissions (Kahn JM, et al critical care medicine, 2015). A population based cohort study (Crow SS, et al, 2017) stated that out of all critical care admissions, 25% were found to be among the paediatric population (Jannet ER, et al, 2016).

Working in a critical care unit, we have met parents who verbalise that their child's return to normal function is difficult and a lot of times they wake up with nightmares. Children are also apprehensive of new situations and stranger anxiety has increased. Parents have also verbalised that children, have started to have behaviours like nail biting and enuresis. This has prompted me to search for literature on the psychological outcomes of critical illness in children and to study the magnitude of the psychological problems in children.

REVIEW OF LITERATURE:
A study conducted in turkey, points out the benefits of mechanical ventilation, its complications, and mortality rates.(Kendirli et al., 2006). There are studies that put forth the various challenges that we face in the Indian scenario with regards to the infrastructure, equipment maintenance, staffing and education of the staff who take care of critically ill patients.(Yeolekar & Mehta, 2008). Paediatric Intensive care is becoming more efficient with the advent of the various protocols and research into child welfare. A lot of contribution has been made by the international community and the various organisations of the United Nations to bring reforms and cater to the rights of children.

NEED FOR THE STUDY:
Impact of critical illness and the physical outcomes in children undergoing mechanical ventilation have been extensively studied previously. Most studies that were carried out earlier have stated a need for further exploration in the aspects of psychological and behavioural terms, as very little information has been researched and published on that score.

HYPOTHESIS:
Critical illness will cause long term psychological distress in children

OPERATIONAL DEFINITIONS:
Critical Illness: Illness or hospitalisation that requires specialised intensive care, assisted ventilation and continuous monitoring for any duration of time.

Mechanical ventilation: Means of artificial ventilation used to assist or replace spontaneous breathing Psychological.

Distress: Feelings or emotions that the child experiences, that hinder their level of functioning. CHILDREN'S CRITICAL ILLNESS IMPACT SCALE (CCIIS) (Appendix 1) by Jannet E Rennick (Rennick et al., 2011) is used to measure the level of psychological distress that the child experiences after a critical illness. Children – refers to the paediatric population between the ages of 6-12 yrs who have survived mechanical ventilation. Assumptions: Any episode of critical illness has adverse effects on the psychological aspects of children, if not addressed.

Limitations: Parents may be unwilling to give consent.

(1) Children may not feel comfortable in sharing details of their fears and anxiety with a complete stranger. (2) Children may feel more ostracised due to their health status and frequent visits to the hospital

Projected outcome:
The study will help-- In Determining the Magnitude Of Psychological distress in Children following discharge from Paediatric Intensive Care Unit. 2.In Creating An Awareness among the health care personnel regarding the importance of psychological care of children admitted in PICU. As a basis for Planning Care Strategies that include modes of adaptation and incorporate psychological care into the child's discharge plan. Strengthen the counselling sessions that happen periodically, conducted by the medical and nursing team. In introducing counselling for children who survived mechanical ventilation as a discharge package and thereafter during follow up. In recommend that psychological rehabilitation should become a part of the discharge and follow up practices. In conducting an experimental design study to assess the effectiveness of psychological counselling in preventing negative psychopathology. Prepare a protocol to help health care personnel in providing psychological care to children who have undergone a critical illness.

DATA ANALYSIS:
This chapter describes the analysis and interpretation of data and study findings from 64 children , who had survived mechanical ventilation. Quantitative data

was collected using standardised questionnaire to assess the parents' satisfaction of care and the level of psychological distress in children who survived mechanical ventilation. A total of 64 children and their parents consented to participate in the study. Total enumerative method of sampling was used as the method of data collection. The questionnaire took 15-20 minutes each to complete. Descriptive statistics and inferential statistics were used for analysing the data. Descriptive statistics such as frequencies and percentages were used to summarise and depict the demographic and clinical variables of the child and demographic variables of the parents. Data is also represented using pie diagrams and bar plots. Pearsons Chi square and Fisher's exact test were used to assess the association between the variables and the level of psychological distress in children. Chi square was also used to test the association between the parents satisfaction of care received in PICU and their demographic variables. The "p" value of < 0.05 was considered statistically 'significant' and <0.001 was considered 'highly significant' The statistical software SPSS version 21.0 was used in analysing the data collected.

The study findings are tabulated and interpreted in the sections as follows,
Section A
• Distribution of children according to their demographic variables

• Distribution of children according to the clinical variables.

Section B
• Distribution of children according to their level of Psychological distress measured by the CHILDRENS CRITICAL ILLNESS IMPACT SCALE.

• Distribution of frequencies children according to the score obtained in Childrens Critical Illness Impact Scale

Research method for this study was designed with the aim of gathering quantitative data regarding the psychological distress and satisfaction of parents of care received in paediatric ICU. The target group (Children between the age 6-12 yrs) were assessed for their level of psychological distress, and parents were asked to complete a questionnaire about their satisfaction with the care received in the PICU A quantitative research approach was used for the purpose of this studyA descriptive cross sectional design of study was adopted to assess the level of psychological distress among children who survived mechanical ventilation and also their parental satisfaction regarding the care received by their children in PICU.

Setting of the study:The study was carried out in the Paediatric Intensive Care Unit and Paediatric High Dependency Unit, Paediatric medical wards, and in the paediatric outpatient department of Christian Medical College and Hospital, Vellore.

Study Population:
• The target study population were children aged 6-12yrs, who survived mechanical ventilation and ransferred from PICU/PHDU to the wards .

• Children attending the follow-up check-ups in Child Health OPD after their discharge from PICU /PHDU with a minimum period of 1 week.

• Parents of children who received care in the paediatric ICU.

Sample:
A sample of 57 children who fulfilled the criteria of inclusion were selected for the study.

A sample of 57 parents who gave consent were selected to participate in the satisfaction survey.

Sample size

SINGLE PROPORTION – ABSOLUTE PRECISION	
EXPECTED PROPORTION	0.25
PRECISION %	10
DESIRED CONFIDENCE LEVEL (1- ALPHA) %	95
REQUIRED SAMPLE SIZE	72

With reference to Jannet E Rennick the mechanical ventilation distress was found to be 25% with a precision at 10% with a desired confidence interval at 95% , the sample size was estimated to be approximately 72.

Formula used to calculate sample size,

$$n = \frac{Z^2 \, 1\text{-}\alpha/2 \; p \, (1\text{-}p)}{d^2}$$

p : Expected Proportion

d: Absolute Precision

1-α/2: Desired Confidence Level Statistical Methods: Data Entry was done using EPI DATA3.1 software. Data Analysis was done using SPSS 16.0 or higher. Descriptive statistics such as Age of the Child , Days of hospitalization shall be reported using Mean±SD for normally distributed variable, skewed variables was reported using Median(IQR). Categorical variables such as gender of the child was reported using Frequency and percentage. The summative score of all the 23 items of the CCIIS tool shall be arrived. Higher the score, worse is the distress. The comparison between the CCIIS tool total score against the socio demographic and clinical variables was assessed using Two independent sample t test / One way ANOVA.

METHODOLOGY:
A total enumerative sampling method was used. All children who have been discharged from PICU/PHDU post mechanical ventilation were included as study participation. PICU register was used as the sampling frame. Every child who falls under the inclusion criteria was included as study participants. An Enumerative sampling method was used. Children were given a self reporting questionnaire – CIIS in their own language Data collection instruments (Children's CriticaI llness Impact Scale (CCIIS)) The instrument used was a standardised tool developed by Prof. Jannet E Rennick, to measure the psychological distress of children who have been admitted to the Paediatric Intensive Care Unit. The tool assessed the child's distressed based on their verbalisation of worries, fears, friends and family, sense of self, and behaviours. The tool contains a total of 23 questions designed to elicit information regarding the above said domains.

Scoring and Interpretation:
Each CCIIS item is scored as a 4-point Likert scale, with total raw scores ranging from 23 to 92. A higher score indicates a higher level of distress.(J. E. Rennick & Rashotte, 2009)

Each item was scored from "4- highly distressed" to "1- not distressed".

The instrument had positive and negative statements that reflect the psychological distress of the child. E.g., A negative statement -'I have trouble falling asleep', and a positive statement – 'I do not have trouble falling asleep'. Both the statements had two choice of responses ,-

1. "really true for me" and 2. "Sort of true for me". The scoring was given by the author, based on the statement- negative statements received a score of 3 and 4 and positive statements received a score of 1 and 2.(J. E. Rennick et al., 2011). The scoring system is attached to the appendix 1 for reference.

Each item was scored once, and all scores were summed together for the final raw score.(J. Rennick, F McHarg, Dell'Api, Johnston, & Stevens, 2008).
To make the interpretation in terms of percentage, the scoring was divided as follows,

80- 100 % - SEVERELY DISTRESSED

60-79% - MODERATELY DISTRESSED

40- 59% - MILDLY DISTRESSED

< 39 % - NOT DISTRESSED

Validity And Reliability
Standardized scale with a content validity of 0.87

Test retest reliability was measured to be 0.75

Validity was measured by Cronbach's α

Ethical considerations:
The study proposal was approved by The Instituitional Review Board (IRB).

The investigator obtained permission from The Medical and Nursing Superintendent of CMC Hospital, Vellore. The investigator also obtained permission from the Medical and Nursing Heads of the Department. Samples were identified by means of the PICU/PHDU register.

APPENDIX:
Instruments in Tamil and English were used most often. The data thus collected was entered in a secure coded computer file, accessible only to the investigator. Confidentiality of the information provided was maintained throughout the course of the study.

The data was collected in three sections for the child and two sections for the parents

Data collection-for the children

Section 1
Contains demographic variables of the child

I. Age

ii. Gender

iii. Education

iv. Religion

v. Ordinal position in the family

Section 2
Contains the clinical variables of the child

i. Clinical diagnosis

ii. Mode of hospitalisation

iii. Mode of ventilation

iv. Previous hospitalisation

v. Presence of co-morbidities

vi. No. of days on mechanical ventilation

Section 3
Self reporting questionnaire (CCIIS) with 23 items measuring the psychological distress of the child who survived mechanical ventilation.
Data collection for the parents

Section 4
Contains the demographic variables of the parents

*   Age

*   Gender

*   Education

*   Family income

*   Employment status

*   Type of family

*   No. of children

*   Area of residence

Section 5
Self administered questionnaire for measuring the satisfaction of care that their child received in PICU during their critical illness (EMAPATHIC 30 QUESTIONNAIRE). Contains 24 items, takes 10-15 minutes to complete.

The pilot study helped in assessing the feasibility of the study. The self reporting questionnaire of the children (CCIIS) and the parents' satisfaction scale (EMPATHIC-30 QUESTIONNAIRE) was found to be appropriate and easily understood by the children and their parents. No changes were made to the scales. The translated version in Hindi & Tamil was also used during the pilot study and they yielded accurate results

The statistical significance was kept at 0.05. Analysis was done using SPSS 21.0.

*   Clinical and demographic variables of the children and demographic variables of the parents are shown using frequency tables.

*   The psychological distress of the children were measured by CCIIS and are shown using frequency table

FINDINGS:
The objectives of the study were,

1. To assess the impact of critical illness on the psychological distress in children who survived mechanical ventilation.

2. To assess the satisfaction of parents of care given to children in PICU/PHDU Of Christian Medical College & hospital Vellore.

Major findings of the study,
*   Majority of the children were in the age group of 6-8 years and 11-12 years(35.9%), 60.9% were boys, and most were practicing Hindu religion (60.9%), majority (71.9%) were studying in middle school.

*   Respiratory illness is the primary reason (40.6%) for mechanical ventilation, followed by Infection (26.6%). 92.2% of the children were emergency admissions, with 82.8% of children with no pre-existing co morbidities.78.8% were on invasive mechanical ventilation and 60.9%were intubated for more than 48 hours.

*   Parents who participated in the study were mostly mothers (84.4%), most were among the age group 30-40 years (50%), and were educated until pri-mary (45.3%). 53.1% of the participants were unemployed, and the total family income was approximately Rs.5000/- to Rs.10,000/- per month(65.6%). Majority of the children were 2nd born (54.7%), living in nuclear families (89.1%), in urban settlements (65.6%).

*   Of 64 children who participated, the minimum score that they had given to the level of psychological distress, was 40 (62.5%) children were moderately distressed and a maximum score of 24 (37.5%) were severely distressed.

*   Of children who participated, the minimum score that they had given to the level of psychological distress, was 64(70%) and a maximum score of 88 (96%), with a mean score of $73.4 + 5.0$

*   The number of parents who were moderately satisfied (70-89%) with the care given in the pediatrics ICU. 63 (98.4%)

*   The scoring that the parents ad given to the care that their children, 94 (65%) being the minimum score and 123 (85%) being the maximum score given, with a mean of $109.64 + 4.4$.

*   The association between the level of distress the children undergo in relation wit their age. gender, education and religion. Out of the 39 male children who participated, 15 (38.5%) were severely distressed and 24(61.5%)of them were moderately distressed. The p value is <0.05, hence not statistically significant. Of the 25 female children ,who participated, 9 (36%) were severely distressed and 16 (64%) were moderately distressed, statistically not significant. **Implications for Nursing:** The implications for nursing are divided into 3 categories - nursing education, nursing practice, and nursing research.

CONCLUSIONS:
The present study suggests that there is a need for awareness about not only physical but also psychological rehabilitation of children who undergo mechanical ventilation. This study also highlights the areas of care that still need improvement from our part, namely, providing appropriate information when requested, and involving parents in decision makinh with regards to their child's care. The study also indicated that providing age appropriate counselling at the appropriate time will lead to a better psychological outcome